

**U.S. House of Representatives
Committee on Energy & Commerce
Subcommittee on Health**

“H.R. 1740, The Breast Cancer Education And Awareness
Requires Learning Young Act Of 2009;
H.R. 1691, The Breast Cancer Patient Protection Act Of 2009;
H.R. 2279, The Eliminating Disparities In Breast Cancer Treatment Act Of 2009;
H.R. 995, The Mammogram and MRI Availability Act of 2009”

Testimony of
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Wednesday, October 7, 2009

Mr. Chairman, Mr. Ranking Member, and Members of the Committee, thank you for the opportunity to testify today about the four breast cancer bills before the committee and provide perspectives from the patient advocate community on other key legislation before your committee. My name is Jennifer Luray, and I am President of the Susan G. Komen for the Cure® Advocacy Alliance and Vice President of Government Affairs and Public Policy for Susan G. Komen for the Cure®. On behalf of the breast cancer patients, survivors, families, friends, researchers, scientists and advocates in the Komen family, thank you for holding this hearing.

Mr. Chairman, this month marks the 25th anniversary of National Breast Cancer Awareness Month. It provides an opportunity for us to reflect on how far we have come over the past two and a half decades and celebrate the great strides we have made in the fight against breast cancer. New discoveries, better screening, community investments and enhanced awareness have helped turned millions of cancer patients across the country into cancer survivors.

Yet while we celebrate our accomplishments, National Breast Cancer Awareness Month is also a reminder of how far we have to go. Almost 200,000 women will be diagnosed with breast cancer this year alone.¹ Sadly, despite all of our advances, we will still lose more than 40,000 of our mothers, sisters, daughters and friends to the disease.² And we still face racial, ethnic, geographic and socio-economic disparities in breast cancer, just as we do in health care across the board. These facts underscore why we must redouble our investment in science and research, and commit ourselves to delivering new discoveries — as well as existing technologies and treatments available today — to patients’ bedsides as quickly and as safely as possible. While we invest in searching for the cures for tomorrow, we must not forget about the women and men being diagnosed with breast cancer today. It’s about saving lives, and that, Mr. Chairman, is why we are here today.

¹ American Cancer Society, “Breast Cancer Facts & Figures 2009-2010.” Available online at http://www.cancer.org/downloads/STT/F861009_final_9-08-09.pdf.

² Ibid.

About Susan G. Komen for the Cure and the Komen Advocacy Alliance

Susan G. Komen for the Cure began with a promise from Ambassador Nancy G. Brinker to her dying sister Suzy that she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure and launched the global breast cancer movement.

Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures. Thanks to events like the Susan G. Komen Race for the Cure® Series, in our first 27 years, Komen has invested almost \$1.5 billion to fulfill our promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world. To continue this progress, Komen will invest another \$2 billion over the next decade into cutting-edge research and community programs.

The Komen Advocacy Alliance, a sister organization to Susan G. Komen for the Cure, is the nonpartisan voice for more than 2.5 million breast cancer survivors and the people who love them. The Alliance's mission is to translate the Komen promise to end breast cancer forever into action at all levels of government to discover and deliver the cures for cancer. With a network of more than 250,000 advocates, the Komen Advocacy Alliance promotes increased funding for cancer research and expanded access to cancer care services for all women.

Komen's goal is to reduce and one day eliminate suffering and death from cancer. To realize this goal, Komen promotes education and awareness to empower women to be advocates for their own health, and we invest in the tools to make it possible. Our investments span the entire continuum of cancer care — from cancer research to early detection to treatment to survivorship. We make significant grants to fund innovative community services, and advocate for improved access to high-quality cancer care and an increased commitment to the fight against breast cancer by the public and private sectors. We believe it is this three-pronged approach — research, community programs, and advocacy — that will make the biggest impact and the most progress toward our promise to end breast cancer forever.

Cancer Research. When Komen advocates for breast cancer research funding, it is as a full partner in the effort to discover and deliver the cures. Neither the federal government nor the private sector can accomplish this goal alone. Over the past three years alone, Komen for the Cure funded \$237 million in research grants to the best minds in cancer science all over the world, to take advantage of new breakthroughs and accelerate treatments for women with aggressive breast cancers that do not respond to current therapies. In fact, a Komen grant has touched every major breast cancer breakthrough in the past 25 years, including the basic discoveries in genetics and biology that have evolved into less invasive, personalized treatments for what was once a “one-treatment-fits-all” approach. In addition, Komen grants helped make possible:

- Discovery of the first breast cancer susceptibility gene (BRCA1), and a test for women to learn about their inherited risk. This has led to very early detection of breast cancer in some women and prevention in others.
- Understanding that breast cancer is not one disease — it is a collection of diseases, each with different characteristics that allow doctors to deliver tailored treatments that are more effective and involve fewer side effects.
- Insight into the role of hormonal factors in breast cancer risk, development and progression, leading to understanding of tamoxifen resistance, tools to identify women who are more likely to develop resistance, and development of new hormonal therapies such as aromatase inhibitors.
- Understanding the role of angiogenesis in providing the blood supply that allows cancer cells to continue to grow and leading to discovery of drugs like Avastin that kill cancer cells by starving them of their blood supply.

- Discovery of signaling pathways ‘turned on’ by the over-expression of HER2 receptors in some types of very aggressive breast cancers and the role of kinase inhibitors as potential therapeutic agents with fewer adverse effects than Herceptin.

Community Investment. Komen Affiliates operate in more than 120 communities across the country, and this year alone invested nearly \$160 million in their local communities to provide underserved populations with access to breast cancer education, screening and treatment. This includes community grants to more than 1,900 organizations that provide free or low-cost mammograms, as well as physical, emotional and financial support for breast cancer patients and survivors. Many Affiliates also fund treatment assistance programs that help breast cancer patients with day-to-day chores and provide monetary assistance with rent, utilities, and co-pays.

Public Policy and Advocacy. The Komen Advocacy Alliance directly engages policymakers and opinion leaders at the state and federal levels. This year, we opened a new office in Washington, DC and have expanded our presence in the nation’s capital. Across the country, our Affiliates work to increase funding for state breast and cervical screening programs, expand access to Medicaid treatment for uninsured women diagnosed with breast and cervical cancer, require insurance companies to cover routine care costs for clinical trials, and require parity in the coverage of oral chemotherapy drugs, compared with intravenous therapy, among other legislative successes.

Breast Cancer Legislation

While we energize science to develop the early detection methods and new treatments that will save lives tomorrow, we must remember that millions of our friends and loved ones do not have access to the detection and treatment methods available today. To fully realize the potential of our investments since the first Breast Cancer Awareness Month 25 years ago, we must:

- **Empower Women** to be advocates for their own health;
- **Expand Access** to breast health services for all women; and
- **Improve the Quality of Care** through care coordination, addressing oncology workforce shortages and provider education.

Each of the pieces of legislation before the committee today will help move us closer to these goals.

The Breast Cancer EARLY Act (H.R. 1740 / S. 994)

The Komen Advocacy Alliance supports H.R. 1740, the Breast Cancer Education and Awareness Requires Learning Young Act of 2009, also known as the EARLY Act. The EARLY Act was originally introduced in the House in March 2009 by Reps. Debbie Wasserman Schultz (D-FL), Sue Myrick (R-NC), Donna Christensen (D-VI) and Rosa DeLauro (D-CT). In May 2009, a similar version was introduced in the U.S. Senate by Senators Amy Klobuchar (D-MN) and Olympia Snowe (R-ME). The EARLY Act will empower young women to take control of their breast health through:

- A carefully targeted public health campaign to teach young women that breast cancer can and does occur in young women, but more importantly to help them establish good lifelong breast health habits;
- An education campaign to increase awareness among health care providers that breast cancer occurs in young women and knowledge of the risk factors for breast cancer in young women; and
- Support services for young women with breast cancer.

The bill’s sponsors have worked closely with our staff and scientific advisors, as well as others in the cancer community, to develop and enhance the language of their legislation. The Senate version of the bill reflects this ongoing conversation by increasing the targeted age to under age 45 and under,

emphasizing evidence-based messaging, and adherence to the peer-reviewed guidelines developed by the National Comprehensive Cancer Network (NCCN), an alliance of 21 of the world's leading cancer centers and the respected arbiter of high-quality cancer care.

Breast Cancer in Young Women. While it is relatively rare, young women do get breast cancer. Each year, more than 25,000 women in the U.S. under age 45 are diagnosed with breast cancer, and almost 3,000 women under age 45 will die of the disease.³ Breast cancer is the leading cause of cancer deaths in women under age 40.⁴ Breast cancer in young women tends to be a more aggressive disease and tends to be diagnosed at later stages than for older women. Younger women tend to be diagnosed with higher grade tumors, larger tumor sizes and a higher incidence of lymph node involvement — ultimately leading to lower survival rates.⁵ Here are a few stories of young survivors:

"I was a senior at Boston University when I first found a lump in my left breast in January 2005 and sought help. Without any follow up testing at all, my provider told me my lump was benign because I had no family history and I was too young. In May, a doctor finally took the lump seriously and ordered an ultrasound because it was practically protruding from my chest. On June 3, 2005 we found out that I had breast cancer. The next week, after a series of tests, we found out the cancer had traveled to my liver. Just two weeks after my college graduation, I found out I had Stage 4 breast cancer. The doctors have given me a 16% chance of seeing my 30th birthday.

"Not a day goes by when I don't wish that my provider had taken this lump more seriously. Not a day goes by when I don't wish I could get those five months back and perhaps change my diagnosis. In the past four years I have had three recurrences, four surgeries and dozens of biopsies. I have been in chemotherapy since my diagnosis in 2005. I live my life in three-month increments because every 3 months I get scans to see if my cancer is growing.

Cancer has touched literally every part of my life. That is what it means to be diagnosed late. That is what I wish I could undo by insisting upon a mammogram immediately. I wish I could tell every student in the US my story so no other young girl is diagnosed Stage 4. The EARLY Act does that for me." – Bridget, Boston MA

"At 25 years old, being diagnosed with breast cancer was the last thing on my mind. I knew that there would always be an increased risk for me because my mother had just been diagnosed three years earlier at age 50. So in my mind I said to myself, 'Oh...I have at least another 25 years to start worrying about it.' I couldn't have been more wrong.

"I moved to Texas in January of 2003. In October I saw a new doctor, who felt something in my breast on my first visit. What was most disturbing was the fact that my former doctor back home that I'd had for the past five or more years thought nothing of a lump in my breast and told me that it was fibrocystic tissue.

"Immediately my new doctor ordered a mammogram. I went the very next day and from there I was told they also wanted a sonogram. Everything was moving so quickly. Within a week I was referred to a breast surgeon who performed biopsies. My surgeon called me back within a few days and asked me to come to her office the next morning. She and I were both teary as she gave me my results and recommended a mastectomy and chemotherapy. The teamwork between my primary care physician, my surgeon and oncologist made my journey less taxing. I credit them with saving my life because what had been dismissed before as nothing could have

³ Number of women under age 45 who will be diagnosed with breast cancer in 2009 includes both invasive (18,640) and carcinoma in situ (6,460). American Cancer Society, "Breast Cancer Facts & Figures 2009-2010."

⁴ Ibid.

⁵ Anders, et al, "Young Age at Diagnosis Correlates with Worse Prognosis and Defines a Subset of Breast Cancers with Shared Patterns of Gene Expression", Journal of Clinical Oncology, Vol. 26, No. 20, July 10, 2008, 3324-3330.

claimed my life as it did my friend Kera who was diagnosed during my battle and died in her twenties just a few short years later.” – Crystal, Dallas, TX

Unfortunately, these stories about young women and breast cancer are not unique. They are repeated 25,000 times a year by women under age 45 who are diagnosed with breast cancer in the U.S. Many didn't know what signs to look for. Others, like Bridget and Crystal, have been told by their providers that they are too young to develop breast cancer, or given a false sense of hope by providers who are overlooking the possibility of breast cancer in a young woman. That is why the EARLY Act, with its focus on providing information for young women *and* their providers, is so important.

Education, Awareness and Empowerment. Ultimately, the cures for cancer will come from an increased investment and commitment to research by the government and private sector, and delivering those cures to patients as quickly and safely as possible. But a key component in reducing suffering and death from cancer, both in older and younger women, is a focus on education and awareness. The EARLY Act is intended to help fulfill that need by encouraging young women to know their specific risk factors, be more aware of changes in their bodies, know when to talk to their medical provider, know what questions to ask, and know what support is available for younger women with breast cancer. By sharing these messages in a carefully targeted, age-appropriate way that is soundly based on the science, we can empower women and provide them with the tools to be advocates for their own health.

Messages directed toward a young population to raise awareness and knowledge about breast health must be done in a careful, responsible manner. That is why the EARLY Act puts the evidence-based education campaign in the hands of experts. The EARLY Act directs the Centers for Disease Control and Prevention to base its outreach to young women on the recommendations of an advisory committee of breast cancer experts, and specifically calls for the messaging to be based on the NCCN guidelines. Thus, as the science evolves — and new evidence-based methods are developed — so, too, will the messaging.

We may not have all the answers, but we have learned much about specific risk factors and early warning signs of breast cancer, and we should share what we know. We are learning, for example, that breast cancer tends to be more aggressive in younger women, and that aggressive types of breast cancer are more common in certain subpopulations like certain African American women. And we know that certain women have increased risk, including women with a strong history of breast cancer at an early age; a family history of breast and ovarian cancers; a family history of male breast cancer; or Ashkenazi Jewish heritage and also have some family history of breast or ovarian cancer.

Since the EARLY Act was introduced, we have seen an outpouring of support from our grassroots network and the young women we serve. They appreciate the attention to this important group of patients that all too often is overlooked by the health care system and the advocacy community. Further, the Komen Advocacy Alliance partnered with the Young Survival Coalition, Living Beyond Breast Cancer and the Breast Cancer Network of Strength to issue a joint statement in support of the EARLY Act. The joint statement is available online at www.KomenAdvocacy.org/EarlyAct. I respectfully request that the report be entered into the record.

While the Komen Advocacy Alliance firmly supports the EARLY Act, we also want to ensure that the funding for this initiative does not detract from existing programs, in particular the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), which serves uninsured and under-insured women. We know that Congresswoman Wasserman Schultz supports the NBCCEDP and appreciate her commitment to ensure that funding for this important program will not be reduced.

Breast Cancer Patient Protection Act of 2009 (H.R. 1691)

The Komen Advocacy Alliance has consistently supported the “Breast Cancer Patient Protection Act of 2009” introduced by Reps. Rosa DeLauro (D-CT) and Joe Barton (R-TX). The Act would amend the Employee Retirement Income Security Act of 1974 to require coverage for a minimum hospital stay

for mastectomies, lumpectomies, and lymph node dissections for the treatment of breast cancer and coverage for secondary consultations.

Decisions concerning a patient's care, including the length of a hospital stay subsequent to mastectomy, lumpectomy or lymph node dissection for the treatment of breast cancer, should be made jointly by the patient and her doctor — not by her insurance company. We are committed to ensuring all Americans have access to affordable, high-quality health care, and we encourage patients to talk with their doctors about all treatment decisions, including the length of any hospital stay.

Mammogram and MRI Availability Act of 2009 (H.R.995)

The “Mammogram and MRI Availability Act,” introduced by Rep. Jerrold Nadler (D-NY), requires group health plans that provide coverage for diagnostic mammography for women age 40 years and older to also provide no-less-favorable coverage for annual screening mammography for women age 40 and older. It also requires group health plans and individual health plans to cover annual screening mammography and annual MRIs for any “high risk” woman. A screening mammogram is performed on a woman with no signs or symptoms of breast cancer, while a diagnostic mammogram is performed to evaluate a breast problem.

The bill is consistent with guidelines recommended by Komen for the Cure, American Cancer Society and NCCN that women at high risk receive annual mammograms and an MRI every year and that women at moderately increased risk should talk with their health care providers about the benefits and limitations of MRIs.

About 80 to 90 percent of breast cancers in women without symptoms in the U.S. will be detected by mammography.⁶ Yet, only 51.2 percent of women 40 and older in the U.S. reported having a mammogram in the last year.⁷ Recent studies suggest that many women in the U.S. are getting their first mammogram later than recommended, not having mammograms at recommended intervals or not receiving appropriate and timely follow-up of positive screening results.⁸ This may lead to more advanced tumor size and stage at diagnosis.

The Komen Advocacy Alliance believes all women should have access to recommended screenings. We have promoted this by seeking increased funding for programs that provide screening for underserved women like the NBCCEDP, advocating for patient protections in the House and Senate health care bills that will increase access to early detection services and addressing other gaps that infringe on access to quality care. Further, the Komen Advocacy Alliance believes that women should have access to the appropriate diagnostic tests, including cancer survivors who need follow-up testing and surveillance.

“I found a lump on the day of my daughter's first birthday – April 2007 – and immediately went to my OBGyn. I was just 36 years old. I have no family history and eventually was tested for the BRCA gene, which I don't carry. It came out of nowhere. I had two biopsies which showed the cancer was pretty much all over my left breast.

“Navigating the health care system was overwhelming. Anyone in cancer treatment should never have to deal with front line customer service representatives at health insurance companies. I repeatedly worked my insurance company over until I was assigned a dedicated person in claims who ended up being a saving grace. As a cancer patient, you have so many doctors and bills you have to coordinate you just have to be able to work with someone internally who is well educated about the claims process.

⁶ American Cancer Society, “Breast Cancer Facts & Figures 2009-2010.”

⁷ American Cancer Society, “Cancer Prevention and Early Detection Facts and Figures 2009.” Available online at http://www.cancer.org/downloads/STT/CPED_2009.pdf.

⁸ Ibid.

“This year my husband changed jobs and we began with a new insurance company. My first horror story with them was that they flat out denied – even on appeal – a breast screening MRI that my oncologist wanted me to have. When I called and spoke with front line customer service reps, they could not even tell me why the test was denied or what to do to get it approved. It was a rough week. Ironically, that day the front page of The Washington Post featured a story about how health insurance companies were cutting costs and it was the patients that would suffer as a result. To make a long story short, I finally found the right person at my insurance company and was able to get the MRI.” – Anna, McLean, VA

Eliminating Disparities in Breast Cancer Treatment Act of 2009 (H.R.2279)

The “Eliminating Disparities in Breast Cancer Treatment Act” by Rep. Kathy Castor (D-FL) amends the Social Security Act to establish a breast cancer treatment quality system in coordination with the National Quality Forum that would develop quality measures for breast cancer treatment by health care providers, with a focus on improving outcomes for underserved women. It also would institute a pay-for-performance payment system within Medicare by 2012 that would reward providers for performance against the new quality measures.

We commend Congresswoman Castor for her attention to the important issue of disparities in breast cancer. We know that there are disparities in access to breast cancer care and breast cancer survival rates: African American women have a 37 percent higher rate of mortality from breast cancer than white women, despite having an overall lower level of incidence of breast cancer.⁹ Improving the quality of cancer care and ensuring access to high-quality care has been a focus at Komen for some time.

An example of Komen’s commitment to reducing disparities by improving quality measures is our partnership with the Metropolitan Chicago Breast Cancer Task Force, which was formed in response to the growing disparity in breast cancer mortality rates between African-Americans and whites in Chicago. The mortality rate for African Americans in Chicago is 68 percent higher than for whites.¹⁰ The Task Force developed action plans that would address three probable causes of the disparity: 1) inadequate access to mammography; 2) poor quality of mammography; and 3) inadequate access to and poor quality of treatment. In June 2008, Komen invested \$1 million toward the creation and ongoing work of the Chicago Breast Cancer Quality Consortium, which will coordinate the collection and sharing of breast cancer quality data; provide rapid cycle improvement support to institutions whose quality of care falls short of the Consortium guidelines; and help coordinate timely breast cancer care for women in need. The Consortium will reduce disparities in breast cancer mortality by instituting breast cancer screening and treatment quality metrics and systems for follow-up care. The important work being done in Chicago illustrates the essential role of quality care in reducing disparities in outcomes for underserved women and parallels the intent of H.R. 2279.

Further, Komen recently joined with the American Society of Clinical Oncologists on a “Quality of Care Initiative” that will address quality issues including cancer workforce issues, access to care, disparities, clinical trials and survivorship, with a focus on breast cancer.¹¹ The initiative will enhance coordination of patient care between oncologists and other practitioners to improve efficiency and patient care. It will also collect data in a breast cancer registry that can be used for practice-based quality improvement. Currently there is no registry that specifically targets outpatient medical oncology care, where about 85 percent of cancer care is delivered. This type of data collection is a fundamental requirement for any performance- or quality-based payment system.

⁹ American Cancer Society, “Cancer Facts & Figures for African Americans 2009-2010.” Available online at http://www.cancer.org/downloads/STT/cfaa_2009-2010.pdf.

¹⁰ Hirschman J, Whitman S, Ansell D. The Black:White disparity in breast cancer mortality: The example of Chicago. *Cancer Causes Control* 2007; 18:323-333.

¹¹ More information about the Quality of Care Initiative” is available online at <http://www.ascocancerfoundation.org/TACF/Our+Donors+and+Supporters/Susan+G.+Komen+for+the+Cure-ASCO+Cancer+Foundation+Collaborative+Commitment>.

Other Issues before the Energy & Commerce Committee

America's Affordable Health Choices Act (H.R. 3200)

The Komen Advocacy Alliance believes all cancer patients deserve access to affordable, high-quality health care. Unfortunately, in today's health care system, not every patient is able to get the care they need. Congress must *consider cancer* as they debate proposals to reform the nation's health care system. Our primary focus is on reforms that will directly affect cancer patients and survivors. As such, the Komen Advocacy Alliance supports insurance reforms in H.R. 3200 that would increase access to affordable health insurance for all, prevent insurance companies from denying coverage due to pre-existing conditions such as cancer, protect patients from high out-of-pocket costs, and increase access to early detection services.

During the August Congressional recess, we asked our network of more than 250,000 advocates to vote on their priorities for health reform and to share their personal experiences with the health care system. Nearly 60,000 Komen advocates have shared these priorities with Congress. Below is an analysis of how H.R. 3200 would address some of the concerns and challenges faced by cancer patients and survivors as they navigate the current health care system.

Access to Affordable Health Insurance. 46 million Americans lack health insurance, and that number is climbing.¹² Many are a pink slip or major medical diagnosis away from losing their health insurance. For example, a cancer patient in treatment who needs to reduce hours or leave a job may lose his/her insurance. Lack of adequate health insurance means lower screening rates, more advanced cancer at diagnosis and lower chances of survival. Patients with private insurance are more likely to be diagnosed at earlier stages, and are more likely to survive at all stages of diagnosis than the uninsured. Cancer patients who are uninsured — and those who were Medicaid-insured at time of diagnosis — are 60 percent more likely to die in 5 years than those with private insurance.¹³

H.R. 3200 will help provide affordable access to insurance through a variety of mechanisms. It would prohibit insurers from excluding patients or charging higher premiums for pre-existing conditions, restrict insurers from charging higher premiums or dropping coverage based on health status, create Health Insurance Exchanges through which individuals and small employers can purchase coverage, and provide credits to help individuals and families up to 400 percent of the federal poverty purchase health insurance. It would also expand Medicaid to 133 percent of the poverty level. These provisions will make health insurance easier to purchase and more affordable. Guaranteed access to affordable health insurance will make cancer care more accessible for all.

"I am a six-year anal cancer survivor. My outstanding medical bills are well over \$100,000. I have no insurance and have applied for every program that I know of for assistance. According to every program, I do not qualify for any assistance. I can't even get disability, so I am dependant on my husband's minimal fixed income. The cancer treatment I got saved my life but left my quality of life less than tolerable...We are stuck in a hole from which there is no escape." — Marcia, Johnson City, TN

Exclusion of Coverage for Preexisting Conditions. Cancer survivors face tremendous hurdles when they try to buy health insurance, because their cancer is defined by insurance companies as a pre-existing condition. Cancer patients or survivors may experience "job lock," in which they cannot leave their current job for fear of losing their health insurance. Even cancer survivors who have been in remission for years with a good long-term prognosis have trouble finding coverage in the individual market because of medical underwriting and the existence of their pre-existing condition.

¹² U.S. Census Bureau, "Income, Poverty, and Health Insurance Coverage in the United States: 2008," September 2009. Available online: <http://www.census.gov/prod/2009pubs/p60-236.pdf>.

¹³ Elizabeth Ward, et al., "Association of Insurance with Cancer Care Utilization and Outcomes," CA: A Cancer Journal for Clinicians, Vol. 58, No. 1, January/February 2008, p.9-31.

H.R. 3200 prohibits health insurers from excluding patients or charging higher premiums for pre-existing conditions. As a temporary measure, until the pre-existing conditions provisions are effective, it also provides for a reduction in the pre-existing condition “look-back” period. Elimination of pre-existing condition exclusions is essential for cancer patients and survivors - people who have battled cancer should not have to battle health insurance companies to find affordable health insurance.

“I am a breast cancer survivor...twice. I have been dealing with it for three long years. We pay \$1,900 per month for insurance on a COBRA plan because no one else will take me on a policy. This is so unfair to add to what a family already deals with when dealt a cancer diagnosis! It affects every family member, emotionally, physically, and financially. The cancer patient takes on all of that burden on top of their own fears and guilt. We are fighting for our lives and need all the strength we can muster up. You lose your hair, your breasts, your eyebrows and your eyelashes. Give us some sense of hope that on top of it we are not bankrupting our families in the process.”
— Karen, Irvine, CA

“My husband’s job was down-sized primarily because of our high cost of medical care due to my breast cancer. The jobs of everyone who had high medical expenses were down-sized. Once the COBRA insurance expired, I was unable to get insurance due to PREVIOUS MEDICAL CONDITIONS. I was finally able to get insurance through the state insurance but [it] was extremely expensive. I had to work two jobs just to pay for the coverage--a lot of stress for someone recovering from radiation & chemo. NO ONE should have to face this!!!” — Stella, Collinsville, IL

Protection from High Out-of-Pocket Costs. Cancer patients with health insurance are not always protected from high out-of-pocket costs, requiring them to deplete their savings or incur thousands of dollars in medical debt. Many health insurance policies have annual and lifetime caps on benefits or other limitations and exclusions. Patients may be exposed to large out-of-pocket expenditures because cancer treatments can be very expensive — some therapies run hundreds of thousands of dollars a year and may require extensive and long-term monitoring and follow up.

The financial impact on patients and their families can be disastrous. A recent study by Harvard University found that half of all bankruptcy filings were partly the result of medical expenses, and 68 percent of those who filed for bankruptcy had health insurance.¹⁴ Further, a national survey commissioned by the American Cancer Society Cancer Action Network shows one in five cancer patients has significantly or completely depleted their savings because of medical costs — one in seven has incurred thousands of dollars in medical debt.¹⁵

Under H.R. 3200, patients will have protections from exorbitant out-of-pocket costs, deductibles and co-pays, with limits of \$5,000 per individual and \$10,000 per family. The bill also prohibits insurance companies from establishing annual or lifetime benefit limits. These measures will help ensure that a cancer diagnosis does not lead to financial ruin.

“I am 60 years old, retired and paying for my own insurance. I have a maximum out-of-pocket of \$14,000 per year. I chose a high deductible because I couldn’t afford anything else. This year I was diagnosed with bilateral breast cancer and already owe \$18,000. It is ironic how ‘maximum out-of-pocket’ does not include co-pays. My treatment plan will extend into next year so I will again incur at least \$15,000. I have no prescription coverage and need to take a cancer drug for five years which cost \$400/month. That is another \$4,800 every year. This is devastating to me.

¹⁴ Himmelstein, et al., “Illness and Injury as Contributors to Bankruptcy,” Health Affairs Web Exclusive, w563, February 2, 2005.

¹⁵ Lake Research Partners and American Viewport conducted the survey, which was sponsored by the American Cancer Society Cancer Action Network, May 1 through 11, 2009, among a national sample of 1,057 adults age 18 and older, in households with cancer or a history of cancer. Available online: <http://www.acscan.org/pdf/healthcare/reports/poll-05202009.pdf>.

I worked hard all of my life and lived a healthy and active lifestyle. Now with one diagnosis, my life is turned upside down.” — Mary, Asheville NC

Early Detection & Prevention Services. Early detection is the key to survival. For example, when breast cancer is detected early, the 5-year relative survival rate is 98 percent, but declines to 84 percent for regional disease and 23 percent when cancer has metastasized or spread to other parts of the body.¹⁶ Women who are uninsured or underinsured are more likely to skip potentially life-saving cancer screenings. In fact, a recent study by the Government Accountability Office reveals that the NBCCEDP only screens about 15 percent of eligible women, while about 26 percent of eligible women are screened by other providers, such as free clinics and mobile vans, some of which are funded by Komen Affiliates. Unfortunately, these resources are limited and often not available in rural or other underserved areas. Shockingly, 60 percent of eligible women do not receive recommended breast cancer screening from any provider¹⁷ – a disturbing revelation that is much higher than previously understood and underscores the need for access to affordable insurance. And for women who do have insurance, even a small co-payment can significantly reduce mammography rates.¹⁸

A renewed focus on prevention and early detection will save lives. H.R. 3200 will improve prevention by covering preventive services in Medicare and Medicaid, eliminating cost-sharing for preventive services, and increasing Medicare payments for certain preventive services. Women who cannot get a mammogram today because they lack insurance or cannot afford co-pays will now have improved access to these services.

“I lost my grandmother to cancer in 1994. She went without insurance for several years before her Medicare kicked in. As a direct result, her cancer went undetected and untreated. When doctors at University Hospital in St. Louis made the diagnosis, we were told that even with radical radiation and chemotherapy that her chances of survival were slim. The doctors said that if she had been seen sooner, that the outcome could be quite different. She passed away 15 months later. Even after 14 years, her passing still affects my life. She was my guardian while growing up and later became my mentor. I still miss her. Because she did not have access to affordable health care, my life was robbed of her joy too soon. NO FAMILY SHOULD HAVE TO GO THROUGH THIS! — Tina, Santa Fe, TX

H.R. 3200, the America’s Affordable Health Choices Act, addresses many important priorities. However, there are two additional issues that should be included in the House health reform bill: extending access to patient navigation services to help guide patients through the complex health care system, and ensuring access to clinical trials.

Patient Navigation. Navigating the complex health care system can be an insurmountable task for patients facing a complicated or chronic disease, especially if they are underserved, have a lower level of medical literacy, or do not speak or read English well. Patient navigators are trained to serve as personal guides and help people overcome obstacles to receiving timely cancer treatment and care. Patient navigation is a proven concept that is cost-effective, promotes prevention, saves lives, and addresses health disparities. This provision is in the bill reported out of the Senate Health Education Labor and Pensions. We respectfully request that the Committee reauthorize and fully fund the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (PL 109-18) for five years, FY2011 through FY2015. Current authorization expires at the end of FY2010.

¹⁶ American Cancer Society, “Breast Cancer Facts & Figures, 2009-2010.”

¹⁷ Government Accountability Office, “MEDICAID: Source of Screening Affects Women’s Eligibility for Coverage of Breast and Cervical Cancer Treatment in Some States,” May 2009. Available online at <http://www.gao.gov/new.items/d09384.pdf>.

¹⁸ Amal N. Trivedi, et al., “Effect of Cost Sharing on Screening Mammography in Medicare Health Plans,” *The New England Journal of Medicine*, Vol. 358, January 24, 2008, pp. 375-383. (Available online: <http://content.nejm.org/cgi/content/full/358/4/375>). The study examined 174 Medicare managed-care plans from 2001 through 2004, which included 550,082 individual-level observations for 366,475 women between the ages of 65 and 69 years.

“Due to cultural and language barriers, not to mention the complexity of our health care system, many are having a terrible time navigating the road between their doctors, oncologists and providers. It’s not right that some of us have access to the most cutting edge treatments, while others are shut out and left mired in a web of confusion. We must ensure all women have access to patient navigators, and are aware of and have access to clinical trials.” — Maria, El Paso, TX

Access to Clinical Trials. Each year, thousands of people gain access to the highest-quality cancer care and receive new treatments before they are widely available by participating in a clinical trial. Millions more benefit from the findings. Yet, while more than 1.4 million Americans are diagnosed with cancer each year, fewer than 5 percent will participate in an approved clinical trial.¹⁹ Some health insurance companies do not cover routine medical care expenses for patients enrolled in approved clinical trials, or refuse to cover complications that sometimes occur during the course of an approved clinical trial. Failure to cover these items may mean otherwise-eligible people are turned away, or are exposed to high out-of-pocket costs when they encounter complications.

The Cancer Clinical Trials Act of 2009 (H.R. 716/S.488) would require group health plans and health insurance providers to cover routine patient care costs for individuals enrolled in clinical trials. The Act would remove a large barrier to patient participation and provide access to many more people. The Komen Advocacy Alliance supports the Access to Cancer Clinical Trials Act of 2009 and respectfully requests that access to clinical trials be included in H.R. 3200.

“A clinical trial saved my life. I had stage 2B cancer and went on a trial to receive Herceptin. I am convinced that the drug saved my life. It should not be so rare that people take part in these trials. We need to educate the public on the benefits of clinical trials, and make it easier for them to have access to trials. I am LIVING proof that it not only will help us find a cure sooner, it can save lives.” — Sharon, Roanoke, VA

These are the stories of real people with cancer who faced real problems with the health care system as it is today. We urge you, as Members of the Energy & Commerce Committee, to ensure that the final bill includes all of these provisions to protect patients and improve care.

21st Century ALERT Act (S. 717)

Finally, Komen would like to remind the Committee that while the bills discussed today are enormously important, the cancer research and care enterprise must be addressed. We are facing a crisis in our investment in prevention and early detection of cancers; in our dedication to innovative cancer research; and in patient access to the highest quality cancer care and treatment. During our Komen Community Challenge tour, a nationwide year-long campaign designed to bring communities and policymakers together to close the gaps in access to care, we heard firsthand from patients, family members, and lawmakers just how severe this cancer crisis is.

The impact of cancer on the lives of ordinary citizens is extraordinary, but often unimaginable to those who have not lived through it. We applaud the late Senator Edward Kennedy and Senators Kay Bailey Hutchison and Dianne Feinstein for their introduction of the 21st Century Cancer ALERT Act (S. 717) last spring. This bill enjoys the support of many members of the cancer community and is critical to addressing the cancer crises. Among other things, the bill would make significant investments in early detection of cancer, facilitate translational and clinical cancer research and improve patient access to high quality cancer care. We know that Rep. Lois Capps and other members have been working on a companion bill to be introduced in the House, and we look forward to working with Congresswoman Capps and the committee on this important legislation.

With the mapping of the human genome and the availability of new medical technologies, there is much potential for new, personalized medicines that are targeted to individual patients and individual

¹⁹ American Cancer Society.

tumors with a reduced risk of side effects. We need more research on early detection and promoting the discovery and development of biomarkers so breast cancers — and all cancers for that matter — can be detected at the earliest possible stage, when cancer is most treatable.

We must remember that many cancers still do not have effective early detection methods. Ovarian cancer is a particularly devastating example: There is no screening diagnostic, thus a diagnosis is most often made after the cancer has spread. When ovarian cancer is detected locally, the survival rate is 93 percent; however, only 1 in 5 cases are detected at this stage, dropping the overall five-year survival rate to only 46 percent.²⁰ Mortality rates are even more disturbing for lung and pancreatic cancers. This has to change.

While health reform should continue to be the Committee's first priority, upon its completion, we urge you to turn your full attention to the Cancer ALERT Act. Despite a few highly-successful cancer therapies, the fundamental goal of the "War on Cancer" launched in the 1970s—to diminish death and suffering—remains largely unrealized. Indeed, cancer now exceeds heart disease as the leading cause of death among people under 85 years old.²¹ The Cancer ALERT Act could change this for the better, and we look forward to working with you on this important legislation.

Comprehensive Cancer Care Improvement Act (H.R. 1844)

The Komen Advocacy Alliance also supports the "Comprehensive Cancer Care Improvement Act" (H.R. 1844), introduced by Reps. Lois Capps and Charles Boustany, as we have in previous Congresses. The Act would provide coverage for comprehensive cancer care planning services within Medicare and will make strides toward a cancer care system that coordinates all levels of care. Cancer patients should have a coordinated plan for treatment and follow-up from the time they are diagnosed through the years of their survivorship. A written cancer plan and the opportunity to review it in person with their doctor will better enable cancer patients to understand the process ahead, monitor their own health, and participate in decisions about their care. Further, a written plan will help coordinate care among a patient's many doctors and providers, reduce medical errors, and ultimately improve patient care.

"I was living in New Orleans when I was diagnosed with breast cancer in 2005. My treatment included six months of chemotherapy to shrink my tumor before having surgery to remove it. After that, my doctors found there was still more cancer in my body, which meant they had to operate again. My second surgery was on Friday August 26, 2005. Three days later, Hurricane Katrina washed away everything in New Orleans – including the results of my last surgery and my doctor's instructions for my follow-up treatment.

"You may not think there was anything fortunate in that story, but let me tell you how lucky I was. Somehow, even as the water rose and people came to rescue us in canoes, I knew I should grab the record I had of my treatment and surgeries. I tell people that I spent seven days with no underwear, but I had my pathology report!

"Like thousands of other Katrina survivors, my family and I lived in the Cajundome in Lafayette, Louisiana for three months. It was there that medical personnel interviewed me and got me to a medical team that would figure out my care from that point forward. Surviving a natural disaster that wiped away my records is an extreme situation. Unfortunately, it is not very different from the confusion that other cancer survivors experience in everyday life.

"When you have cancer, you suddenly have several doctors caring for you through different stages of treatment. One doctor performs your surgery. Another gives radiation. And then there's

²⁰ American Cancer Society "Cancer Facts & Figures 2009." Available online at <http://www.cancer.org/downloads/STT/500809web.pdf>

²¹ Ahmedin Jemal, et al., "Cancer Statistics, 2009," CA: A Cancer Journal for Clinicians," Vol. 59, No.4, July/August 2009. Available online at <http://caonline.amcancersoc.org/cgi/content/full/59/4/225>.

chemotherapy, which is usually prescribed by an oncologist and given to you by a nurse. Others draw blood and perform scans. If you're lucky, you also have a social worker helping you through all this while you try to carry on with your family and keep your job. If you have other health issues – such as diabetes, high blood pressure, kidney disease or lung failure – all those doctors need to understand your cancer and the effects of its treatment.

“But guess what? The system does not have a way to coordinate all that. Cancer survivors usually have to figure out a lot of new and scary issues on their own. They have to do it while they are feeling sick, stressed out and scared. And they have to do it quickly.

“Patients need to talk to their doctors about their cancer care plans before they start their treatments, and doctors should give their patients a paper copy of that plan. It is hard to hear anything after, ‘You have cancer.’ And then you have a lot of things to learn and a lot of decisions to make – a lot of things to talk over with your family. A written plan would have helped me, and I know it would help many other survivors.

“And when survivors like me finish their therapies, they should be given something on paper that describes all of their treatments, the possible side effects, what they should do to monitor their health and who will be following up on their care. There's so much to remember- no one can possibly keep it all in their head.” Patricia, New Orleans, LA

Conclusion

Thank you, again, for the opportunity to testify before this committee. As we observe the 25th anniversary of National Breast Cancer Awareness Month, we should take the time to reflect on the last two and a half decades — the accomplishments, the triumphs, the losses. We should take the time to think about the daunting challenges that lie ahead of us over the next 25 years. If we are to help alleviate and one day hopefully end suffering and death from cancer, we will have to commit ourselves to an increased investment across the cancer continuum, in research, early detection and treatment — and make a commitment to enhancing community resources and promoting education and awareness. We look forward to working with you, the other organizations represented on this panel, and our partners in the cancer community to reignite our efforts in the fight against cancer. Thank you.